The Adolescent Alone

Decision Making in Health Care in the United States

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Introduction
The Adolescent Alone: "You Got Nobody in Your Corner"

Carol Levine, Jeffrey Blustein, and Nancy Dubler

Imagine the waiting room of an adolescent health clinic at an urban medical center. Some patients are accompanied by a parent, another adult, or a friend. Most of these adolescents see the doctor alone, but occasionally they ask the accompanying person to come into the office for a post-examination discussion. Other patients come to the clinic alone, tell no one about the visit, and do not ask for outside advice or help in making decisions about medical treatment.

Tammy, for example, a fifteen-year-old, has lived a few months at a time with various relatives since her mother died of AIDS two years ago. She has had asthma since childhood and the stress of her recent past has exacerbated her illness. No one in her family seems aware of her declining health or that she needs continuing support to adhere to her medication regimen. Seventeen-year-old Robert, on the other hand, does not even have an unconcerned relative; he has been living in shelters and on the streets since he left home after his mother's latest boyfriend issued an ultimatum: "Either he goes or I go." Robert has had several episodes of sexually transmitted diseases; he has finally agreed to an HIV antibody test. He has no close friend or relative to talk to should the result be positive. James, sixteen years old, left home after a fight with his parents over his announcement that he is gay. He has been drinking heavily and tried to commit suicide once. A counselor at the health clinic has convinced him to see a doctor for psychiatric evaluation. James has no one to help him sort out the options for in-patient or out-patient treatment. Amelia, fourteen years old, lives with her elderly grandmother who speaks no English. She believes that Amelia's rapid weight loss is caused by Amelia's spiritual impurity, and has been treating her with traditional medicine. A teacher has convinced Amelia to visit the clinic, where extensive testing has been recommended. Amelia is sure her grandmother will not approve, and she herself does not know what to believe.

These are a few of a special group of adolescents – we call them *unsupervised* or *alone.* This is a book about the ethical and legal issues that arise in their encounters with the medical care system. These youth are "alone" because they do not have a supportive relationship with an adult in a birth, foster, adoptive, or chosen family.

There is no trusted adult who is consistently available to guide and monitor their passage to adulthood and to help them evaluate medical options and make appropriate decisions. In the past several years clinicians, researchers, and other service providers and policy analysts have become increasingly aware of such adolescents. Their numbers have increased, as later chapters will show; in addition, their health care needs have become more complex, for example, because of the emergence of AIDS as a major threat to youth.

The book is the result of a project that was supported by grants from the Fan Fox and Leslie R. Samuels Foundation and the American Foundation for AIDS Research. The editors were the project coordinators. Nearly all the authors were participants in the project; a few were invited later to expand our scope. The project undertook an analysis of the ethical issues that practitioners were confronting with their adolescent patients and clients who faced health care decisions largely without adult guidance. Practitioners found that the prevalent legal and ethical principles were inadequate.

One problem is that the existing principles are ambiguous about adolescents, who are in transition from childhood to adulthood. Even the age range defining adolescence varies according to the setting, the professional methodology, and the purpose of the definition. The authors in this volume have selected different age ranges as appropriate to their discussions. Competent adults are legally and ethically empowered to make decisions for themselves based on their values and preferences, their personal experiences, their religious beliefs, the availability of alternatives, their level of pain and suffering, and, increasingly, on the economic consequences that follow from their decisions. For children the equivalent principle is that parents make medical decisions on their behalf. Children, especially young children, are assumed to have neither the cognitive skills nor the mature judgment to make complex choices that may have far-reaching health consequences. Parents are empowered to make medical decisions because they are assumed to be in the best position to determine the best interests of their child, they know and love the child, and they can interpret medical options in light of their family history and values. Moreover, they have to share the consequences of the decision, which may affect not only one youngster but also siblings and other family members. Parents, through public or private insurance, are also the primary source of payment or eligibility for medical care. For the majority of families, and for the majority of decisions, this paradigm works well enough. Certainly no other authority – medical, legal, or other professional – has the same privileged status as the parent in our society.

But the paradigm has clear limits. First, it is best suited to infants and young children, not adolescents. In general, adolescents have achieved a degree of intellectual and emotional maturity that surpasses that of young children, yet they are not fully adult. Another limitation, now recognized in state statutes, is that adolescents need some medical services, such as treatment for sexually transmitted diseases, for which parental consent or even notification may present serious barriers. The most important limitation, in terms of the population addressed in this volume,

is that the model assumes the presence of at least one parent who has a stable, nurturing, and supportive relationship with the child. The lack of such a parent or other adult is precisely what makes these adolescents alone.

In the traditional schema for decision making for children, parents do not stand alone. In making difficult health decisions for children, generally a therapeutic alliance emerges among the pediatrician or the adolescent medicine physician, the parents, and the child. As the child matures through adolescence, adults gradually incorporate his or her participation and preferences. More or less together they choose among the alternative plans for treatment or – occasionally in the case of terminal illness – nontreatment..

Because of the state's *parens patriae* obligations to protect the welfare of children, the state, through the courts and the child welfare system, may also play a role. The trigger to invoking the power of the state is a judgment by a physician or other care provider that the child is suffering from or is at risk for "medical neglect." Parents, physicians, and the state each have rights, duties, and obligations in making medical decisions for children. However, the boundaries may be unclear or disputed.

Adolescents alone are unsettling precisely because they do not fit the established pattern. We began by thinking that we were discussing rare cases – orphaned, abandoned, homeless, "street kids," youth in prison or detention centers, outcasts of family and society. They were the epitome of *the other.* We quickly saw, however, that many adolescents, while not literally alone, are functionally alone. Throughout the discussions among the editors and authors, and in the working meetings that produced the chapters in this book, we asked, who are these youth? How did they come to be "alone"?

There are many answers. Some of these young people have been orphaned because their caregiving parent died of AIDS, other diseases, drug use, or violence. Some are functionally alone because their parent or grandparent or other nominal caregiver is mentally ill or addicted to drugs or alcohol, or is simply overwhelmed by poverty or other pressures. Some gay and lesbian youth have been ostracized by their families. Some adolescents have run away from homes where adults physically or sexually abused them. Some are in foster care, where they may have both biological and foster parents but no one to trust with private information and concerns. Others have parents or other adults who drift in and out of their lives, promising support, occasionally providing it, but withdrawing it at will and often when the youth needs it most.

Some adolescents alone are involved with their families but live apart from them for economic or other reasons. Some are recent immigrants to the United States, living in extended families where they are the only ones who speak English. These adolescents, caught between two cultures, with very different concepts of disease, medicine, and decision making, may be surrounded by loving family but alone in the modern medical setting. Some adolescents do not *appear* to be alone – that is, several adults may claim to represent the young person's interests – but these adults have neither legal guardianship nor continuous relationships. The involvement of

many adults, none with clear parental authority or responsibility, may engender conflict or ambivalence rather than support.

As the chapters and cases in the book illustrate, adolescents alone do not fit into a single category. Some of the youth described in this book have been cast outside society's boundaries of acceptability. Through the dismal circumstances of their lives, they have become "the other." In Chapter 8, Michael Clatts and colleagues eloquently describe the struggles and feelings of youth who are truly alone. But "the other" also looks more familiar. In Chapter 9 on adolescents in in-patient settings, Betty Levin moves toward this end of the spectrum. The youngsters she describes have adults in their lives but the social dislocation and poverty they have experienced jeopardize what might otherwise be supportive relationships.

There is an even broader range to be considered. Adolescents alone are not confined to poverty-stricken areas or city streets. Health care providers everywhere may encounter such youths in their offices, managed care plans, school clinics, or hospitals. These youths' aloneness may, in fact, be harder to recognize because they do not have the distinguishing characteristics of youth who live on the streets. Examples are lesbian or gay youth still establishing their sexual identity or youth whose parent's addiction to drugs or alcohol is concealed by the trappings of middle-class conventionality.

What does it mean to be alone? One of the youths interviewed in Clatts's study put it eloquently: "You're by yourself, you got nobody in your corner, nobody sticking behind you, no type of support." The needs of this group of adolescents are complex and urgent. When there is "nobody in your corner, nobody sticking behind you," the transition to adulthood is often marked by insecurity, instability, and outright danger. In conventional adult terminology, these adolescents are sometimes called *hard to reach* or even *unreachable.* Yet they must not be ignored or abandoned. Although many of their most pressing needs lie outside the health care arena, their contacts with supportive health care providers may offer an opportunity to obtain a measure of the acceptance and support they have not received from their parents. Most have experienced traumatic childhoods that have brought them to adolescence with a host of prior losses. Adults have failed them repeatedly. Their adolescent years may be the last chance for many to attempt to achieve a productive and healthy adulthood.

The following sections of this introduction briefly discuss the societal changes that have influenced the growth of this population, some developmental issues, the philosophical underpinnings of concepts of parent–child relationships and adolescence, and the main themes that emerge from the chapters and case studies.

Changes in Family Structure and Functioning

What has happened to produce this growing number of unsupervised youth? Although *family* is an enduring concept, what the term means in any given society at any given time may vary considerably. As Donzelot (1979) pointed out, the fam-

ily is not a "point of departure . . . a manifest reality, but . . . a moving resultant, an uncertain form whose intelligibility can only come from studying the system of relations it maintains with the sociopolitical level." Families are, in other words, social as well as biological constructs.

We believe that a definition of family that is congruent with contemporary American life should be broad but not unlimited. If everyone counts as family, then family loses its special meaning. If only a few count as family, then our understanding of family is impoverished. What separates family from friends and strangers is not just blood or legal ties but an emotional quality of commitment, continuity, and stability. The essential characteristics of these relationships are permanence (at least in intention), commitment to mutuality of various forms of economic, social, and emotional support, and a level of intimacy that distinguishes this bond from other, less central attachments.

Using these parameters, Levine (1991) provides a good working definition of family:

> Family members are individuals who by birth, adoption, marriage, or declared commitment share deep personal connections and are mutually entitled to receive and obligated to provide support of various kinds to the extent possible, especially in times of need.

This definition, written with adults in mind, speaks of a level of reciprocity that children are not able to provide because they are dependent on others for their most basic needs and nurturing. The deep personal connections and commitments that define family, however, are typified by parents' responsibilities toward their children. A group of adults who took good care of each other but neglected their children would not, by this definition, be fulfilling the obligations that are essential to family.

Throughout the world families are changing in ways that put at risk one of their most basic functions: nurturing, socializing, and supporting the children that are born into them or come to depend on them. A Population Council report (Bruce, Lloyd, and Leonard 1995) outlines several relevant global trends:

- As a result of decreasing fertility rates and the dispersal of family members, families and households are generally getting smaller. There are fewer people in family support networks to take care of children and other dependents.
- Even though families have fewer children, the burden on working-age parents to support older and younger dependents has increased. Children become independent at later ages and require more educational investment to prepare them to become self-sufficient. When women marry, they tend to do so at later ages.
- Multiple marriages are common, creating a complex set of relationships for children and an "uncertain claim on parents' attention and income." Many children do not live with both parents, and do not receive adequate emotional attention and economic support from either or both parents. The proportion of female-headed households has increased.
- Women's participation in the formal labor force has increased while men's has declined, placing more economic responsibility on women, not just women who are heads of households. At the same time, men have not balanced their decreased economic opportunities and responsibilities with an increase in child-rearing responsibility.

One far-reaching result of these large-scale trends is that children's well-being is often jeopardized because of their family's adverse economic circumstances.

These global trends are evident in the United States. According to the 1990 U.S. Census, 73 percent of children under age eighteen are living with two parents, a decline from 1960 of 88 percent (Roberts 1995). These two-parent families may not both be biological parents. Of all children in two-parent families, a little more than half are being reared by both biological parents. One in three African-American children living in a two-parent household is living with a biological mother and a stepfather.

The number of single-parent families has increased dramatically since 1970, when there were 3.8 million families, or 12.9 percent of all families, headed by a single parent. In 1991, the number had tripled to 10.1 million, or 29 percent of all families with children. In almost 90 percent of these families the single parent was the mother. More than half (55 percent) of the African-American children in the U.S. today are being raised by one parent, arguably the largest percentage since slavery. In 1960 that percentage was 22 percent. In the same three decades the percentage of white children living with one parent tripled to 19 percent.

In 1970 nearly 400,000 babies were born to single mothers; in 1989 that number had more than doubled to more than a million, or 27 percent of all births. Although the increase in never-married women with children is particularly steep among educated and professional women, an estimated 47 percent of families headed by single mothers live in poverty, compared to 8.3 percent of two-parent families. The number of unmarried couples grew from 523,000 in 1970 to 3 million in 1991, with an estimated 40 percent of these couples having children.

These complex changes are the result of many interacting economic, political, cultural, and personal factors. We reject simplistic and moralistic views that look backward to a golden age that never was when families lived problem-free as long as everyone, especially women and children, stayed in place. Families come in many different shapes and sizes: "blended" families of divorced and remarried partners with children; lesbian or gay couples or single women or men with biological, foster, or adopted children; grandparents raising grandchildren; aunts and uncles raising nieces and nephews; oldest children raising younger siblings; and an array of other combinations of individuals, both adults and children. Such alliances are often viewed as abnormal, but this is a skewed and narrow view, even of American families. As one commentator remarked, "*Leave It to Beaver* was not a documentary" (Coontz 1993).

Diversity in family structure, greater control of reproduction, and more varied educational and economic opportunities for women do not by themselves create problems for children. Nor does poverty, except for extreme deprivation, always threaten family commitments. Children can be nurtured and supported in diverse family structures and through difficult economic and family situations, as long as there are adults who love them, remain committed to caring for them, and are capable of doing so. It is clear, however, that changes in family life, especially those

brought about by economic deprivation and shifts in the labor market, have not been addressed by policies and programs that attend to the needs of dependent children. Family structures that do not fit a particular legal, social service, or medical outlook are at a disadvantage in dealing with those systems. Although families have changed, systems have not.

It is also clear, as the chapters and case studies in this volume show, that for a variety of individual and systemic reasons – substance abuse being arguably the most destructive – some parents and other adults have failed to act as protectors of their children. They have abandoned them literally and emotionally, ignored their needs for supervision and guidance, and acted inconsistently and unpredictably. As these children grow to adolescence, many enter the category we have identified as unsupervised or alone. In many aspects of their lives, the traditional parent–child relationship, in which the parent acts as supportive nurturer, has never worked. If that is the case, the paradigm will not work in the health care setting.

Adolescent Development and the Search for New Paradigms

The emergence of this new category of adolescents presents challenges to prevailing paradigms of family decision making and principles of medical ethics. Adolescents in general have always been at the margins of these paradigms, presenting clinicians and parents with often difficult decisions in judging a young person's capacity to make autonomous choices. Testing those limits is one of the tasks of adolescence. Adolescents alone stretch the margins even further, giving clinicians more discretion, perhaps, but also more qualms about the extent to which it is ethically justifiable and clinically prudent to allow adolescents to make their own health care decisions.

From a developmental perspective, adolescents are in the final stage of becoming adults and are functioning independently of their parents. This is a major step for at least two reasons. First, although the adolescent has been taking small steps toward independence almost since birth, full independence is contrary to the major assumptions and habits of the adolescent's lifetime. Second, childhood has become, through experience and concrete evidence, a familiar place, whereas adulthood has been glimpsed only vicariously and is still uncharted territory.

All children are engaged in the process of developing their own unique identities and becoming autonomous persons, but adolescents have reached the stage where they need, want, and should be encouraged to test their decision-making skills in making the increasingly important decisions in their lives. They have also reached the stage where their basic cognitive skills are likely to be substantially similar to those of adults, even though they lack the experience of adults. Moreover, adolescents have a well-developed system of preferences and values. These values may to some extent reflect the special pressures of adolescence, especially the need for peer approval, and if so may evolve as the adolescent matures. Nevertheless, they are the contemporaneous system by which the adolescent defines himself or herself

and the foundation from which the more refined set of adult preferences, values, and behaviors will grow.

Adolescence is also a time of sexual awakening. The internal forces driving this powerful force, whether encouraged or discouraged by culture and family, may be overwhelming. Although American culture has increasingly acknowledged, and through advertising and the media even encouraged, adolescent sexuality, society also expresses stern disapproval of sexual activity. It is often sexual activity, as well as disease, that brings young people to the health care system.

Many authors in this volume address the complex questions concerning unsupervised adolescents' capacity to consent to or refuse medical treatment and recommend practical ways of involving adolescents in their own health care decisions. In order to put these specific concerns in a broad ethical context, the next section discusses the main themes and concepts that have appeared in philosophical writings about adult–child relations, childhood, and adolescence.

Philosophical Background

In order to place the concerns of this book in a larger ethical context, it is necessary to examine the main concepts and themes that have appeared in philosophical writings about childhood, adolescence, and adult–child relations. Most adolescents grow up in families and, in the contemporary ethics literature on family relationships, questions about the grounds and limits of parental authority are often asked with adolescents in mind. In addition, although philosophers have not addressed the specific problems posed by the group studied in this book, namely unsupervised adolescents, the substantial literature on ethical issues in childhood occasionally has considered whether and how far the analysis extends to adolescents.

Philosophical writing on the ethical foundations of family life has a distinguished history, although, for the most part, interest in the moral aspects of parent–child relations has been subordinated to more general political concerns. Among writers of the modern period like Bodin, Hobbes, and Filmer, the family served as a focal point of debate on the nature and justification of political authority. To be sure, the relationship between familial and political institutions was not a totally new concern in this period; indeed, it had been a recurring theme of social and political philosophy since Plato's *Republic* and Aristotle's *Politics.* But the emphasis in the modern period on parental authority definitely reoriented thinking about the family and gave new prominence to issues of obedience and discipline in family life. In contrast to the ancient Greeks, parental authority was not regarded merely as something to be reflected on or understood or as one element of a larger problem of family–state relations, but as something on which to focus moral judgment.

After Locke's devastating critique of patriarchalism in *Two Treatises on Civil Government,* (1690) and in no small measure due to its influence, philosophers who wrote on the family became less preoccupied with larger normative questions about the political organization of society, although their views on these matters certainly

influenced their thinking about the family. Rousseau and Kant, for example, wrote at length on the moral and intellectual education of children, emphasizing individual autonomy as the goal of both endeavors. And although interest in the foundations of parent–child relationships waned somewhat in the philosophical writing of the first part of this century, in recent years moral philosophers have increasingly turned their attention to questions about the interpretation and justification of parental authority.

The following propositions are commonly accepted by philosophers of the family. First, parental authority cannot be justified only, or even primarily, in terms of the interests of parents. There is some disagreement about the extent to which parents' own interests may be legitimately served by the exercise of authority over their children, but no one seriously argues that parental authority exists solely for the benefit of parents. Rather, parental authority is for the good of children, and justified only to the extent that children cannot yet be presumed able to make decisions for themselves. Second, parental authority, if justified at all, must encourage and adjust to the developing capacity of children for independent judgment. It must be aimed at bringing children to the point where they no longer require continual adult protection and supervision, and can care for themselves, at which point parental authority properly ceases.

Adolescence, however, poses special problems. It both challenges our beliefs about the appropriateness of parental authority and complicates our understanding of its scope. Indeed, over the past three decades, an expanding body of professional literature has questioned our traditional assumptions about the boundaries of adolescent decision making in general and health care decision making in particular. Contemporary moral philosophy's contribution to this rethinking of adolescence has principally consisted of asking questions about the rights of young people, and about whether and to what extent the arguments that secure adult rights apply to adolescents as well. Philosophers, of course, are not the only ones who have been attracted to the language of rights. Appeals to children's rights have also played a significant political and rhetorical role. At the same time, there is a significant undercurrent of ambivalence in our society about where to set the general limits of children's legal rights and about whether adolescents should be considered children or adults for purposes of deciding what rights they have. This ambivalence reflects an underlying uncertainty about the moral status of young people, a subject that requires and has received close philosophical examination.

In order to clarify what is at issue in debates about the rights of children and adolescents, it is useful to begin with some basic distinctions that appear in philosophical discussions of moral rights. The rights that concern us here are *claim rights* rather than *liberty rights*, although some philosophers may define these terms differently. Claim rights can themselves be divided into negative rights to noninterference and positive rights to services, and imply corresponding obligations on the part of others. The negative claim rights are held against "the world at large" and imply obligations of all others not to interfere with the right holder in the exercise

of his or her right; hence, they are called general obligations. The positive claim rights (for example, children's rights to food and shelter) are held against some specific individuals (their parents) and imply obligations only on their part to meet certain needs of the right holder; hence they are called special obligations. This principle that every claim right implies a corresponding duty is referred to in the literature as the correlativity of rights and duties thesis. Liberty-rights, by contrast, are simply liberties or permissions (the right to apply to a particular college or for a job); they are equivalent to a lack of obligations in their possessors, and imply no obligations whatever in others.

A further issue concerns the primary function of claim rights, and this can be explained in either of two ways. To quote philosopher L. W. Sumner (1987), "The interest conception treats rights as devices for promoting individual welfare. . . . On the other hand, the choice conception treats rights as devices for promoting freedom or autonomy." The former depicts right holders as "passive beneficiaries," the latter as "active managers." Although the interest conception can be thought of as incorporating the choice conception, the interest people have in being free and autonomous agents argues for interpreting them as distinct conceptions.

The prevailing view in the philosophical literature is that children have a number of positive claim rights, including the means for ensuring survival and healthy physical growth, affectionate care by adults, and an education that equips them to participate in the life of adult society. These rights can be straightforwardly justified on welfare grounds. The water gets murkier, however, when we consider whether the choice conception can be applied to children to yield additional rights. Arguably children are entitled to some measure of autonomy during childhood, and not just because, as future autonomous adults, they currently have an interest in developing capacities for self-determination. (This argument is based on the interest conception.) But the key question is the extent to which and the matters about which children should be allowed to make decisions for themselves. With young children the answer seems clear enough: the rights that are most important for them are positive claim rights, which do not accommodate much moral room for independent decision making. But over the course of adolescent development, the conditions for actually possessing rights to make certain decisions for oneself are normally satisfied, and there is a blurring of the bright line separating young children from mature adults with respect to the possession of rights.

Not all philosophers agree that the interest conception of rights should be the dominant one, even among young children. Some so-called child liberationists, such as John Holt and Howard Cohen, have taken a radically different view (Holt 1974). Child liberationists argue in part that, with respect to the possession of legal rights, children make up an oppressed group and are, in this respect, like women and members of certain racial minorities. But liberationists are not just concerned about legal rights: whether explicitly or implicitly, they rest their claims about legal rights on other claims relating to the *moral* rights of children – specifically, that children have all the moral rights of adults. This sweeping liberationist position has

struck many commentators as extremely implausible, and philosophers have responded to it with assorted versions of what might be called "the argument from incompetence." The classic statement of this position is found in Locke:

> To inform the Mind, and govern the Actions of their yet ignorant Nonage, till Reason shall takes it place, and ease them of that Trouble, is what the Children want, and the Parents are bound to. . . . Whilst [Man] is in an Estate, wherein he has not *Understanding* of his own to direct his *Will*, he is not to have any Will of his own to follow: He that *understands* for him, must *will* for him too; he must prescribe to his Will, and regulate his Actions. (Locke 1963)

Similarly, the utilitarian philosopher Jeremy Bentham argued:

> The feebleness of infancy demands a continual protection. The complete development of its physical power takes many years; that of its intellectual faculties is still lower . . . . Too sensitive to present impulses, too negligent of the future, such a being must be kept under an authority more immediate than that of the laws. (Bentham 1838–1843)

A fuller statement of the incompetency argument goes like this. In order to exercise liberty, individuals must have autonomy, that is, be able to make decisions on their own. They can only do this if they have relevant knowledge and understanding, sufficient experience to predict the consequences of their actions, knowledge of their own interests, and the ability to act voluntarily. Young children, however, are deficient in these experiences and abilities. Hence, they do not have the same moral rights as adults.

As stated, this is a rather crude argument and certainly some qualifications and refinements are in order. It is fair to say, however, that most philosophers who have written about children are in broad agreement with this position. But if the sweeping liberationist posture seems untenable for this reason, a narrowly circumscribed liberationist position, one confined to adolescents, is perhaps not so easy to dismiss. Here the debate between the liberationists and their so-called protectionist opponents – those who emphasize that children have rights to assistance and care from adults rather than rights to self-determination – becomes more complicated and interesting. (For further discussions, see Purdy 1992.)

One reason this more focused liberationist position is harder to dismiss than the sweeping one is that scepticism about the reality of older children's current immaturity seems more warranted than scepticism about the current immaturity of younger children. The immaturity of young children seems to be a necessary and inevitable feature of human development, although it is possible that changes in child-rearing practices can affect their capacities for independent decision making. If youngsters were given more freedom to act independently and were expected to take responsibility for the consequences of their actions, we might find them not as immature as we have supposed. But the extent to which their apparent inability to act maturely can be significantly altered by changes in our behavior toward them seems to be severely constrained by ineradicable features of biological maturation. In contrast, the capacities of adolescents for mature decision making seem to be

more heavily influenced by adult expectations and rearing practices. As social scientists have pointed out, not every society regards adolescence as a distinct stage of human development (Keniston 1976). Many cultures do not recognize an extended period of preparation for adulthood beyond early childhood; young people are expected to take on adult roles much earlier than they do in our society, and they appear to function adequately in the adult world of their society. Of course, we cannot infer that adolescence does not exist as a distinct developmental stage from the failure of some societies to recognize it as such. However, awareness of other cultural practices and their consequences should at least occasion some scepticism about our own society's views of child development. Perhaps our adolescents would demonstrate a greater capacity for independent decision making if we gave them the opportunity to do so.

Some (moderate) adolescent liberationists are satisfied if they can persuade us to take a less rigid view of human development than that which our culture usually assumes. But others go further, maintaining that our current treatment of adolescents retards and deforms their development, thereby preventing them from realizing at a much earlier age their potential for mature choice and conduct. According to this view, our practices *create* immaturity – they do not *respond to* necessary features of human development.

Clearly this view presupposes social consensus on the indicators of maturity. Anthropologists report extreme variability in how cultures define maturity and adulthood, both with respect to the rights and responsibilities that characterize adulthood and the age at which persons achieve adult status (Group for the Advancement of Psychiatry 1968). It is possible to understand the strong liberationist claim this way: According to our society's criteria of functional maturity, adolescents are (relatively) immature. However, it is only because of our failure to treat them as the equals of adults that they fail to satisfy these criteria to the extent that they do.

Some might cite the case of unsupervised adolescents as a counterexample to this liberationist thesis. They might argue that, although these adolescents have significantly greater independence than so-called normal adolescents who must still answer to their parents to some degree, unsupervised adolescents do not generally display greater maturity. Indeed, they frequently display less. But, even granting this – and that is not the position taken here – the liberationist has a ready response to the objection. The liberationist can claim, indeed any reasonable liberationist must claim, that adolescents will mature more rapidly if they are granted the freedom to act independently, but only in the context of other concurrent social changes. The result would be very different in the case of unsupervised adolescents, the liberationist maintains, if their entrance into responsible adulthood were supported and facilitated by wide-ranging changes in social practices that affect them.

Despite this effective rejoinder, the liberationist view remains unconvincing. To describe the immaturity of adolescents as a social construction is to make an empirical claim, which must be tested by empirical means, such as large-scale experi-

mental trials comparing different child-rearing strategies, as well as social and legal practices affecting youth. The outcome of these trials, assuming their feasibility, naturally cannot be known in advance, and until we can tease out the respective contributions of nature and nurture, a moderate liberationist view of adolescents is the only sensible one to adopt. Human development is contingent on a variety of factors, and contemporary thinking generally concedes that both variable environmental and relatively invariable psychological and biological factors play a significant causal role. Although it is foolish to ignore the extent to which children and young people are shaped by the influences to which they are exposed, neither should it be supposed that they are infinitely malleable and that, under favorable social conditions, they would function well in adult society if they were freed of adult-imposed controls.

Finally, it should be noted that while philosophers have performed an important service in pressing the issue of adolescent rights, the issue of rights refers to only one dimension of value in the relationships that make up the family. Adolescents often live in their parents' home and continue to be materially dependent on them well after they have acquired adult moral rights, and these circumstances should be considered when there is a question of parental infringement of their rights to freedom. What adolescents may gain by having their rights acknowledged must be balanced against possible serious damage to other values such as love, trust, and loyalty in relation to their parents. Unsupervised adolescents, of course, do not have relationships of this sort with their parents, but a similar caution about the need to balance their rights against other values is in order. For even if unsupervised adolescents do not have *parents* to whom they can turn for guidance and emotional support, other opportunities for forming trusting and supportive relationships with adults may be available and should not be overlooked. Health care providers and others who interact with unsupervised adolescents during periods of stress or crisis must bear this in mind.

Themes of Adolescence and Medical Decision Making

This book is divided into three parts. The first contains essays authored by experts in the fields of adolescent medicine and adolescent development, psychiatry, epidemiology, ethics, law and anthropology. The second is a series of case studies with commentaries, and the third is a set of ethics guidelines for practitioners.

Part I provides information and concepts essential to understanding the complex demographic, societal, legal, and medical framework in which adolescents alone are confronted with health care decisions. It also contains a moving personal essay by psychiatrist Francine Cournos on growing up an orphan in foster care and the impact of that experience on emotional development and decision making (Chapter 6). This essay is not only important in its own right but also in reminding us that, in contrast to other more exotic areas of inquiry, we have all been adolescents. Many who criticize "today's kids" would probably rather not revisit their own teenage

years. A post-adolescent college student once commented to his parents: "I'd like to explain to you why I was so silent for the last five or six years of growing up; adolescence is very embarrassing."

To a greater or lesser degree every adolescent is or feels alone. There may be occasional discussions with friends or family, and perhaps some sharing with teachers or mental health professionals, but many critical events are anguished over in solitude. Experiments with relationships and behaviors are part of the task of being an adolescent. They provide the raw material from which personality, preferences, and goals are shaped. But shaping the raw material is often a turbulent and confusing process.

Adolescents live in a continuum of settings, opportunities for education and employment, and availability of financial and material support. In their opening chapter, Audrey Rogers and Susan Newcomer define the category of adolescence, most commonly set at ages ten to nineteen, the middle years between childhood and adult status during which individuals undergo dramatic psycho-social-physical changes at substantially different rates. Clearly the attempt to discuss any such variable category in fixed terms risks overgeneralizing.

However, key characteristics of the group emerge from this overview. By the year 2000, 31 percent of adolescents in the United States will be nonwhite; current estimates indicate that 7 million high-risk youth have only a limited potential for becoming productive adults because of serious problems at home or school; HIV infection may be as high as 8 to 21 percent among certain subgroups of adolescents at risk. Of the youth who are HIV positive, the vast majority have histories of sexual-risk behavior. Many are without health insurance, although most have access to specialized clinics. But, in this age of managed care and the health consumer revolution, many such "boutique" clinics are disappearing. The notion that the indigent could always rely on the public health system is increasingly challenged as publicly supported clinics and hospitals fail to meet the fiscal and organizational demands of managed care companies. It is worth noting that before 1995 the academic medical centers controlled 5 percent of the hospital beds in the country, but provided more than 50 percent of the uncompensated care. Savvy street youth often knew how to access care from this endangered resource.

Nancy Leffert and Anne Peterson expand the discussion in Chapter 2 by identifying and analyzing markers of adolescent physical, psychosocial, and contextual development that may be affected in degree or in timing by the traumatic circumstances that leave adolescents without adult guidance or a secure, predictable environment. There is a wide variety in the changes that accompany adolescent development, such as different relationships in family, school, and peer group. The impact of these changes may be more stressful when the adolescent lacks adult support or is in the midst of family crisis, such as homelessness. Extremely deprived environments may inhibit cognitive and psychosocial development and make the adolescent alone vulnerable to peer and adult pressure to engage in high-risk sexual and drug-using behavior. At the same time, resiliency, exhibited through coping

skills and other protective behaviors, may help adolescents through troubled times. Health care providers, Leffert and Petersen advise, can help increase adolescents' capacity to make decisions by providing a supportive, anxiety-reducing atmosphere.

In Chapter 3, Neal Hoffman provides a comprehensive survey of adolescent health problems essential to understanding the chapters and case studies and commentaries that discuss specific medical decisions. Synthesizing a wealth of recent data, Hoffman sketches a picture of a segment of the adolescent population with a variety of chronic and acute unmet health care needs. Remarkably, health care providers discuss the risks of sexually transmitted diseases to sexually active youth in only 1 percent of office visits. In an era of HIV infection, it is hard to conceive of a more inadequate match of needs and services.

This chapter also destroys the myth that all adolescents are healthy and have little need for the health care system. The reality is that adolescents are at risk for traumatic injuries, broken bones, fractured spines and serious burns (think of the risks of working at fast-food counters). They are beset with mental health problems and with depression, and suicide attempts are not rare in the population. It is sobering to realize that 30 percent of the completed suicides are by gay and lesbian youths and that 90 percent of nicotine-addicted adults began smoking as adolescents.

Prenatal care and abortion are central to the health of young women who are pregnant; these services are diminishing. Access to specialized oncology care is important for youth with cancer; many childhood cancers actually have a reasonable rate of cure if care is timely and consistent. We often think of the chronically ill older adult but rarely think that chronicity is a problem of youth. Hoffman describes adolescents with sickle cell disease, asthma, cystic fibrosis, and hemophilia and shows how these conditions become the defining characteristics of the youth's life. The differences in decision making between acute and chronic conditions is a theme that recurs in many authors' work.

Abigail English, in a particularly elegant and nuanced discussion in Chapter 4, untangles the thickets in the legal landscape of adolescent health care that has been articulated by case law and statute over the last several decades. Historically parents have had extensive authority over their minor children until those children reached the age of majority or became legally emancipated through marriage, service in the armed forces, or living apart and managing their own affairs. Although few adolescents are legally emancipated, many are living in circumstances that affect their legal status as well as their access to health care. Providers struggle with uncertainty about the capacity of minors to consent on their own for health care, as well as their obligation to maintain confidentiality of medical information. Access to care often requires an independent ability to pay; English describes the currently available array of funded programs, noting that managed care will alter the landscape. Some barriers to care are specifically legal, and others have legal underpinnings. English cautious that removing these barriers, while essential to improving adolescent health, will require concerted advocacy by a broad range of actors.

Jeffrey Blustein and Jonathan Moreno tackle the daunting task of creating a morally coherent framework for the decision of an adolescent to accept or refuse care. This intermediate time of life, neither child nor adult, has always been troubling for care providers and ethicists. Given the variability in underlying intelligence, emotional sophistication, developmental success, relationship to parents and authority figures, and character, how can we have rules about the moral appropriateness of choosing? The law, as Abigail English points out, has created an ostensibly clear framework: parents decide for their nonadult children. This framework is punctured by small and huge exceptions: minors can give consent for treatment of sexually transmitted diseases and can obtain contraception and consent for abortion in certain states and under certain circumstances. Can moral analysis be as variable and quixotic as the law?

Blustein and Moreno construct a theory based not solely on the usual analysis of the concept of decisional capacity but also on the notion of *enduring characteristics* that support the concept and fact of a self. Valid consent, they argue, presupposes a self that can articulate values to apply in the process of choosing. Further – but appropriately – complicating the discussion, the authors opt for a concept of *decision-specific* capacity and reject a mechanically imposed *absolute* standard for empowering choice. As with adults, whose capacity can also vary based on age, intelligence, experience, and disability, Blustein and Moreno argue that after the age of fourteen or fifteen, there should be a presumption that the adolescent has the ability to provide ethically adequate informed consent. This presumption of capacity presents care providers with the space in which to balance the obligations of self-determination and beneficence.

They also argue that an additional obligation for adolescent providers is not only to respect autonomy but to actively engage in autonomy-promoting activities. This obligation of active intervention in the decision-making process is one of the morally significant features of the provider role. As part of this obligation they highlight the notion of informed consent as a "process," not merely an event. It is by engaging the adolescent over time in this process, by using the contacts for discussion, education, and support, that providers fulfill the obligation of advocacy.

Whereas these are generic statements applicable to the evaluation of moral capability of all adolescents, there are special considerations for the adolescent alone. For adolescents alone, care providers must create a characterological and personal profile from available data about the time of abandonment, the emotional effects of such wrenching events, and the ancillary supports that were available and might have filled the void. This youth-specific evaluation must precede decisions about the moral acceptability of various decisions and must consider issues of self-esteem, control of drives and impulses, temporal perspective, cognitive abilities and development of trust – a full agenda for the time-constrained, overworked professional dealing with the adolescent alone. Unrealistic? Maybe. But absolutely essential to distinguish those youth who can provide morally valid informed consent from those who must be protected from their ill-considered or self-destructive

behaviors. Respecting the appearance of autonomy without the substance turns respect for persons into abandonment.

Chapter 6, as already noted, introduces personal experience and self-examination into the discussion. Francine Cournos describes how she and her siblings became orphaned and how, "while acting like a miniature adult," she hid the "very needy child who suffered from depression, distrust of adults, an inability to make any new intimate connections, and a tremendous loss of a sense of structure."

This personal insight makes her review of the impact of parental death particularly rich. She explores the notion of trauma, the silent companion of every adolescent alone, and argues that events can trigger self-examination and growth or destruction of trust and the collapse of earlier developmental accomplishments. Feelings of helplessness and meaninglessness hover at the outskirts of conscious and unconscious existence.

Following an elegant review of the psychological, psychiatric, and analytic literature on the adolescent alone, Cournos reflects on her childhood experience. Remembering the experience of having a needle removed from her foot and the rational and irrational threads of thought and emotion this event provoked, she writes:

> Adolescents who are alone have a terrible dilemma. They have a developmental need to break away from their parents, but their parents have beaten them to the punch. They need continuous adult involvement, but it feels like the wrong time to begin again. This may result in an exaggeration of the normal adolescent posture of simultaneously wanting and refusing help.

In Chapter 7, Andrew Boxer, Judith Cook, and Gilbert Herdt address a poorly understood group of adolescents alone – the population of gay and lesbian youth who self-identify as gay during their teenage years. They point out that consideration of the homoerotic as a part of the human condition is politically charged and controversial within medicine and public health as well as within society. Because of the stigma attached to gay gender orientation and behavior, the process of constructing a gay or lesbian identity carries with it the danger of isolating experiences.

The authors' prospective longitudinal study of a cohort of gay adolescents in Chicago, using individual interviews and anthropological ethnographic research, provides the basis for observations on and generalizations about growing up gay. The authors assert that self-identification as a gay person occurs at about age sixteen but is based on desires and fantasies that may go back to the preadolescence age of nine. Sexual development, they note, is an ongoing process rather than a set of stages. Furthermore, some heterosexual activity is compatible with a developing gay gender identity. Given society's general attitude about gay persons, it is not surprising that the investigators found discrepancies between the mental health profile of gay youth and their heterosexual counterparts.

Nevertheless, the authors end on a hopeful note:

> The narratives of the youth reveal the very opposite of stereotypes that portray the murky past of the closeted, shameful, homosexual mythology. These youth gener-

> ally regarded themselves as pioneers of a new generation whose special nature affords an insight into the timeless struggle to be human. Far from being mentally disturbed, sexually fixated, or anti-social, as studies in the past have portrayed such youth, we found them to be courageous, intelligent, and healthy adolescents grappling with the many challenges involved in coming out so early in the life course.

At the same time, many of these youth are functionally alone because ashamed and punitive parents have withdrawn love and support.

The last two chapters in this section and the cases that follow focus on the lived existence of youth on their own. The reality is emotionally compelling, intellectually challenging, and morally complex. Michael Clatts and his co-authors have worked among homeless youngsters in New York City, a population among the most impoverished of any specially identified group. The authors estimate that as many as two million youth in the United States are homeless at any time with some 200,000 residing as permanent residents of the streets. They comment that:

> . . . it is apparent that large numbers of youth have become part of the population living on and from the streets, a social and economic environment in which they are dependent upon the vagaries of the street economy. This is a precarious and often violent world in which these young people do what they can to stay afloat. Often this means exchanging sex for money, food, shelter, and drugs.

Not surprisingly, these youth are exceptionally vulnerable to disease and poor health outcomes, including high rates of STDs, tuberculosis, HIV, pregnancy, and abortion. Despite their numbers, little is known about the reasons for this degree of homelessness and about the consequences for these youth. Chapter 8 reviews existing data and new ethnographic studies, and examines the lives of these youngsters from the perspectives of freedom and independence, the sense of loss and depression, the harshness and violence of everyday life on the streets, the struggle with hunger and exhaustion, the effect of watching others get sick and die from AIDS, the lack of trust even among peers, and the tremendous barriers that confront these youth when they try to leave life in the streets. In richly evocative quotations the authors confront the reader with these sad and troubled lives. This shameful portrait of adult neglect – this is, after all, the rich United States, not a poor developing nation – leaves us with admiration for the outreach workers who forge connections with these youth and link them with increasingly scarce health and counseling services.

Part I closes with a gripping chapter by Betty Levin. An anthropologist, she spent part of a recent sabbatical year as an observer on the adolescent service and the Neonatal Intensive Care Unit of a large urban medical center. Her observations provide an excellent intellectual bridge from the adolescent alone to the huge number of adolescents who, while not formally alone, have fragile, undependable adult support systems.

Levin notes that none of the youngsters whom she observed was technically alone. However, the vast majority were part of chaotic families where the guardians

had such serious problems that they "were not able to provide appropriate support." Therefore, in many ways, these adolescents were alone. This assertion is clearly supported by the stories in this section and by the case studies that follow in the next section. Having explored the emotional, intellectual, and moral development of youth, readers can see how these youngsters are left to the kindness and decisions of strangers. The real deciders about medical care are the providers themselves who not only sift and structure the choices but basically direct the result.

In the cases Levin describes, there appears to be scant scrutiny, by adolescent or family member, of the risks, benefits, and alternatives to care. Rather, random relationships and emotional needs substitute for a rational process of consideration and consent. Even in involved families the barriers of class and education mean that physicians basically make the decisions. Physicians are not riding roughshod over families. Rather, families and adolescents in Levin's study consider that these are *medical* decisions, in which they do not expect to participate. This is not a trivial finding. It provides one more example of the lack of fit between the theory of informed consent and its reality. Especially where there are imbalances of race, class, gender, education, and ethnicity, the doctors call the shots. Whatever papers are signed and permissions are given, it is the care providers who decide.

It has been long recognized but rarely discussed that the norm of informed consent is honored for all patients – adult or child – more in the breach than in the observance. In most cases the physician or care team decides what care is appropriate and presents their conclusion to the patient and sometimes family – and then the patient agrees. The instances of disagreement make legal cases and sometimes headlines, but they are the rarity in medical practice. Dialogue, choice, and preferences are all goals to which care providers aspire. Most decision-making processes, however, fall far short of reaching this level of discussion and collaboration. If this is the case for adults, and we submit that it is, then the model of the adolescent alone choosing an option for care without parental or other adult involvement is just one more step on a continuum. Once the power of physicians as decision makers has been acknowledged, distinctions among patients are diminished. In this sense, then, the adolescent alone is just like most of us, whatever our age, education, income, or experience.

This awesome reality imposes stringent additional ethical obligations on the medical care professionals involved in any case. The theory of the allocation of decision-making authority in medicine assumes that there is an informal system of checks and balances in which the physician proposes and advises and the patient and family question and choose. But if that is not the case, and Levin's chapter indicates the shortcomings of the model, then care providers must challenge each other to arrive at the best care for the patient. They must struggle to discover and apply the values of the patient and to arrive at an ethically justifiable decision.

Part II contains nine cases followed by commentaries authored by scholars in adolescent medicine and development, law, ethics and public policy. These are real stories about real people, with only names and identifying characteristics changed.

In some cases there are several commentaries; in others only one. The purpose of the commentaries is to bring a multidisciplinary analysis to the cases. No attempt has been made to bring the authors into agreement or to give them a single point of view. Although readers might wish for a neat resolution, this does not often occur. In this way the cases are true to life.

The third and final section of the book brings us back to the initial concept that animated this project. This project began as an attempt to create ethics guidelines for health care providers who treat adolescents in all the categories we have defined as *alone.* The guidelines distill, although do not necessarily agree with, the many points of view expressed by project participants who became authors in this volume. Like other ethics guidelines, these are not legal rules nor regulations that carry sanctions. Rather, they present salient ethical principles and practices that should be considered in individual decision making. They are intended to be flexible and to encourage reflection, while at the same time recommending the outer bounds of permissibility and the inner bounds of ethical requirement.

This project, and the resulting book, has been an intellectual and emotional journey for the editors and authors. We have seen how the most vulnerable among us are both different from and like everyone else. We invite readers to share the milestones and detours that have brought us to this juncture.

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